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The use of Skype and telephone interviews in sensitive qualitative research with young people: experiences from the ROCCA continence study

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In the UK, it is estimated that around 900,000 children suffer from continence problems (daytime wetting, bedwetting, soiling and constipation) (PCF, 2014). For the majority, these problems will resolve with age; however for those with more severe problems, they can continue into adolescence and adulthood (Yeung et al., 2006; Swithinbank et al., 1998; Hellstrom et al., 1995; Kyrklund et al., 2012., Joinson et al., 2016). Epidemiological studies estimate that the prevalence of continence problems in 11-20 year olds is around 2-3% for daytime wetting, 2-2.5% for bedwetting and 1-1.5% for soiling (Public Health England, 2013; Joinson et al., 2016). The impact of continence problems on quality of life is comparable to other paediatric conditions such as asthma and epilepsy (Bachmann et al., 2009), and have been shown to have significant negative effects on self-esteem, schooling, mental health, and general wellbeing (Zeedyk et al., 2003; Bower, 2008).

Despite the prevalence and impact of continence problems, this remains an under-researched and poorly understood issue in the adolescent population. In 2014, work started at the University of Bristol's Centre for Child and Adolescent Health on a research project, funded by the Medical Research Council. This mixed methods study included an in-depth qualitative study exploring the impact of continence problems on adolescents' everyday lives, including social and romantic relationships, mental health, education/school, social activities, and goals and aspirations for the future. Participants aged between 11-20 years who were currently experiencing a continence problem were recruited from across the UK. Due to the widespread geographical locations of the participants, it was decided that Skype and telephone interviews would be appropriate as well as face to face interviews. The aim of this article is to explore the benefits and challenges in conducting Skype and telephone interviews, supplemented with an arts-based participatory approach, with children and young people.

The study

Participants were recruited through five paediatric continence clinics (four in England and one in Scotland), and through an advertisement on a paediatric continence charity website (The Children's Bowel and Bladder Charity, www.eric.org.uk). Eligible participants were between 11 and 20 years, currently experiencing continence problems (bedwetting, daytime wetting, or soiling) or who previously experienced these problems after the age of 10, and able to speak and understand English. Participants attending paediatric continence clinics were given a study information pack by their clinician. Those recruited through the advertisement were sent an information pack by the research team. Ethical approval was given by the National Research Ethics Service Committee South West - Central Bristol (14/SW/0059). The researcher contacted all interested participants by phone to describe the study and answer any questions.

In-depth semi-structured interviews were conducted with twenty young people aged between 11 and 20. Of these, 9 were female and 11 were male; 6 experienced bedwetting, 5 daytime wetting, 5 both bedwetting and daytime wetting, and 4 had soiling problems. Participants were given the option of being interviewed by Skype, telephone, or face to face for those within a 40-mile radius of Bristol. Eleven chose Skype and 9 chose telephone. Very few participants were recruited from the local area, and those that were preferred not to have a face to face interview, no specific reasons for given for this preference.

Interviews were conducted by one researcher (KW) and lasted between 34 and 99 minutes (mean 65 minutes). Data collection and analysis were conducted in parallel after completion of the first five interviews. Early analysis was used to refine the topic guide and to further explore emerging areas of interest. Interviews were audio recorded, fully transcribed, and imported into the software package NVivo10. Inductive thematic analysis was carried out following guidelines of Braun and Clarke (2006). Following completion of the first five interviews, each transcript was read and the data were free-coded across all transcripts. A selection of three transcripts were also independently free coded by the study team (CJ and HC). Codes were discussed and compared with all members of the team in order to further refine coding and to maximise rigor (Tracey, 2010). An initial set of agreed codes were set up

within the NVivo10 database and any new codes identified from further interviews were discussed within the team and added to the coding framework.

Art-based participatory research: development of a participant activity pack

A concern in conducting this work was the sensitive nature of the topic and the suitability of interviews for young people, particularly at the lower end of our age range. One to one interviews are commonly used with adults and have been used to great success in qualitative enquiry, however this type of data collection requires more thought in relation to child and adolescent participants. It was felt that on such a sensitive and stigmatised topic as incontinence, reliance on a traditional set of interview questions might yield data lacking in richness and detail. Much work has been done exploring the best way to gain insight into children's experiences from a research perspective and on child-centred data collection (e.g. Mitchell, 2006; Darbyshire, MacDougall & Schiller, 2005; Barter & Renold, 2010). Qualitative work with children should take into account children's skills, capacities, and development (Carter & Ford, 2013). Rather than seeing children as less developed adults and using simplified versions of adult data collection techniques, child-centred approaches see children as experts in their own worlds and recommend using data collection techniques which are sensitive to their competencies and capacities (Clarke & Statham, 2005; Punch, 2002; Kirk, 2006).

For this reason, myself and the team decided that the interviews would be supplemented with an arts-based participatory approach. Art-based approaches (e.g. performance, poetry, diaries, crafts, drawing, storytelling, and play) have greater resonance with children's lives compared to traditional interviews, and provide additional narratives through which to explore their experiences (Carter & Ford, 2013). These techniques can help to redress the power imbalance between the researcher and participant by allowing the participant to have some control over the interview process. Due to the remoteness of many participants and not being able to rely on face to face situations, I chose to use visual prompts and drawing.

A participant pack was developed in tandem with the interview topic guide. The pack contained instructions on how to use it, questions to think about in advance based on the

topic guide questions (see figure 1), and one page for each section of the topic guide with a graphic illustration (see figure 2). It was intended that the pack could be used by participants in advance of the interview to start thinking about what they would like to talk about and reduce the uncertainty of what to expect. During the interviews it could be used as a prompt to start discussions on different topics.

Figure 1: Preparatory questions

Questions to think about

About me
What do you like to do in your spare time?
Do you have any hobbies? What do you do at the weekend?

Food and drink
What food and drinks do you like/not like?
Are there any foods or drinks you avoid to help with your continence?

Who is in my life?
Who do you like spending time with?
Is there anyone you talk to about your continence problems?

Who lives in my house?
Who do you live with? Do you share a room with anyone?
Do you stay over at friends' houses or have friends to stay at your house?

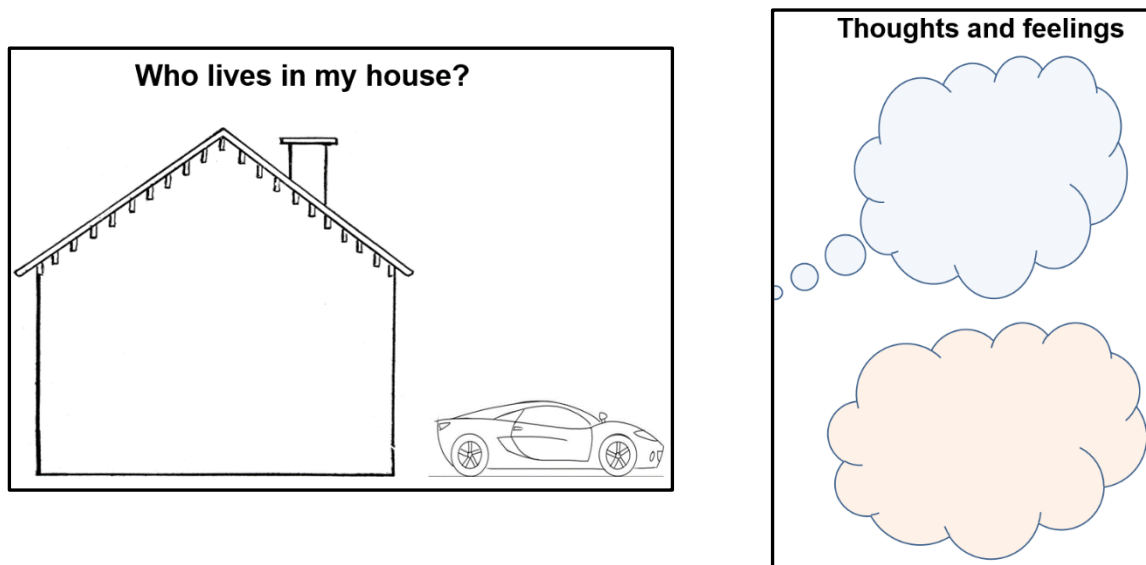
A typical day
What do you do on normal week day?
Does your continence problem affect you at certain times of the day/night?

Practical issues
What happens when you have a wetting/soiling accident in the day or night?

Thoughts and feelings
How does your continence problem make you feel?
What do you think about your continence problem?

Tips and tricks
What advice would you give someone with a continence problem?

Figure 2: Example topic guide pages

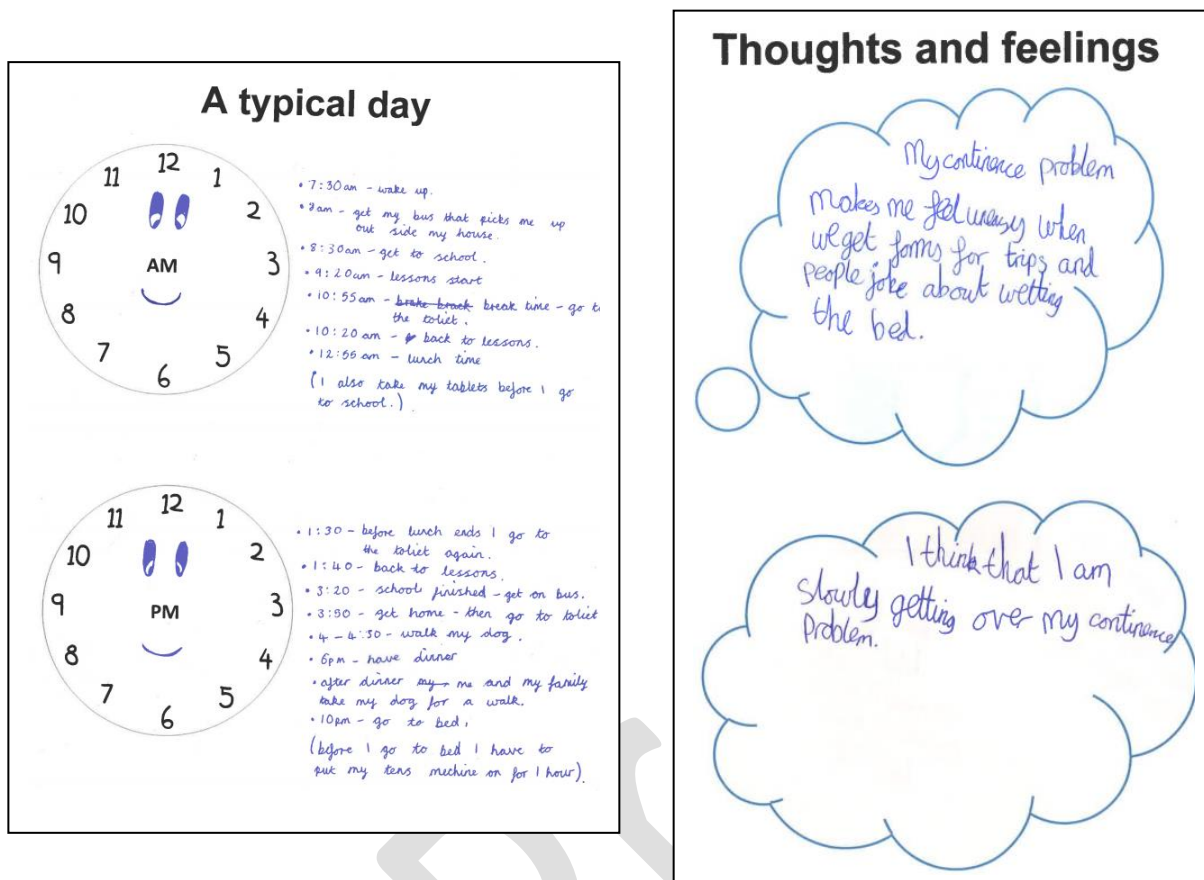


Both the topic guide and the activity pack were taken to two young people's advisory groups in Bristol. These groups were made up of secondary school children aged between 13-14 and 16-17 years. The groups helped to ensure that the activity pack was age-appropriate and easy to use, and offered advice on how best to approach the more sensitive questions, such as dating. The pack was sent to participants in advance of the interview in addition to a patient information sheet, and consent/assent forms. If the participant decided to use the pack, they were asked to return it after the interview to supplement data analysis.

Using the activity pack

The use of the activity pack varied among the participants. The feedback I received from the participants was that being able to see the type of questions they would be asked in advance was beneficial and helped them to feel less anxious about the interview. Younger participants had a tendency to draw rather than write, or use a combination of both; older participants wrote notes or used the pack as a prompt to think about the topics but did not write anything down. Figure 3 shows pages from two participant packs.

Figure 3: Examples of how the activity pack was used by participants (ages 15 and 11)



During the interviews, participants who had used the pack to prepare referred to their notes or drawings as a basis for starting discussions. During Skype interviews using a video link, many participants held their notes or drawings up to the camera for me to see. Participants who had completed some or part of the activity pack appeared to have given more thought to the interview questions and how they felt about their continence problem. Their notes also offered a starting point for discussion on their own terms, such as asking them to explain their drawings or to give more details on what they had written.

The dependence on the pack during the interviews varied among participants. For participants who were more at ease discussing their continence problem, their interviews tended not to follow the structure of the pack but tended to be highly fluid and led by the thought processes of the participant. During these interviews, the pack was used as a checklist to make sure no areas of discussion were missed, or as a method of bringing the interview back in focus if discussions went off topic. I found the pack most useful during interviews with participants who were less talkative and required a higher level of

prompting (this applied mostly to younger male participants). During these interviews, the pack was used more like a work book with each section being discussed in turn. If participants brought up other areas of thought or discussion then these were followed, returning to the pack when needed.

Challenges in conducting Skype and telephone interviews

Technical issues

Using remote methods of data collection comes with basic technical challenges. Skype video calls are dependent on both the participant and interviewer having working webcams, audio, and a stable internet connection. During the Skype interviews, both audio and connection problems were experienced. Skype videos occasionally disconnected, abruptly stopping the interviews mid-discussion. Although they could be re-started, this disrupted the flow of interviews and was particularly problematic during sensitive discussions. During both telephone and Skype interviews, some audio problems were experienced, particularly with sound quality and volume. An additional speaker plugged into the computer was found to improve this; however in some cases it was still difficult to hear participants properly, and I needed to ask them to repeat themselves. As with the disconnection, this hindered the flow of the interviews. The most successful interviews were those using home telephones rather than mobiles, and Skype video interviews on computers used in quiet rooms with a stable connection.

Building rapport and picking up on body language cues

Building rapport with the participants is a vital part of any interview. It helps to put the participant at ease and facilitate greater trust, resulting in richer and more detailed data (Dickson-Swift et al., 2007). Reading non-verbal cues and body language is central to effective communication and can be of great help during qualitative work. Interviewers can use these cues to gauge mood, engagement, and use mirroring techniques to facilitate rapport. During Skype video interviews, visual cues were limited by the small focus of the camera only showing participants' faces or head and shoulders, and on some occasions by the video lagging behind participants' speech.

A key challenge during telephone interviews was interpreting whether pauses in speech were due to the participants thinking about what to say or to their being finished with a particular topic. The strategy I used to deal with this was to explain that during the interview I would give the participant time to think, and that there may be some silences.

Parent involvement

Due to the age of the participants, parents were present during some of the interviews. During telephone interviews, it was common for a parent to be present in the background, but not directly talking to the interviewer, whereas during Skype video interviews some parents sat with the participants and contributed to the interview. Ethical approval did not cover the inclusion of their contribution within analysis, therefore any parent data was not included as part of the analysis process.

Whilst it is important to make sure a participant feels comfortable during the interview process, the presence of a parent can be challenging. Continence problems can have an adverse effect on the whole family and may result in arguments or negative reactions from parents, as reported by some of the participants in the study. Whilst a parent is present, participants may feel unable to disclose these matters or feel restrained in talking about other sensitive issues (e.g. dating). This was particularly evident in one interview where the parent was present for the first half of the interview. When the parent left the participant alone, the participant offered far more in-depth information about the extent of her problem, non-adherence to treatment and hiding her medication, and the death of a close friend, which she believed had significantly impacted on her continence problem.

After seeking advice from colleagues, I developed several strategies for managing parental presence during interviews. Firstly, if the participant was under 16 and needed parental consent, time was taken during the initial phone call with the parent to listen to their story and experiences. Many had experienced difficult journeys in accessing treatment, with their child's continence problem causing significant stress and concern. Very few had been given the opportunity to discuss this outside the family and it was clear that they had a lot they wanted to say. Secondly, the expectations of the interview and the focus of the interview on the child's experiences were made clear. I recommended that at least part of the interview

was conducted without the parent being present, but participants were reassured that if they wanted their parent to be present during the entire interview that their wishes would be respected. During the initial chat with the participant they were told it was up to them if they wanted their parent with them, and they did not have to if they didn't want to. Thirdly, at the start of an interview with a parent present, I talked about this noting their presence, and suggested that we check in again after some time to see if the participant would be happy talking by themselves.

The most significant challenges arose when a parent remained present and were actively involved in the interview, rather than being there for support. On these occasions, it was difficult to ensure that the participant was given an opportunity to talk and consider different issues. In face to face interviews, it is easier to manage this with body language and positioning, but this became more challenging remotely. To address this problem, I verbally brought the interview back to the participant by using phrases such as "your mum / dad has said X, what do you think of that?" or more assertively "I'd really like hear what Brian* thinks about this now". Another strategy was highlighting how well the participant was doing, for example "Jess* is doing really well with these questions, I'd like to hear more about what she thinks".

Benefits in conducting Skype and telephone interviews

Participant recruitment and sampling

A common pragmatic restriction in qualitative work is the geographical location of the participants. Face to face interviews require travel time and expenses, which often means the location of participants is constrained by the distance from the research site. Conducting interviews by Skype and telephone removes this restriction entirely. For this study, participants were recruited from across England and Scotland, with the ability to include any eligible participants with a working telephone or internet connection in the UK. This is a considerable benefit as it allows for a much more diverse sample to be achieved. In addition, removing the need to travel to participants' homes saved researchers a lot of time. In many studies, researchers may need to spend most of their work day travelling in order

to conduct one interview, but in this study, all the interviews were conducted at the research site.

Participant control and power dynamics

An important factor to consider in conducting qualitative work with children and young people is the power differential between the participant and the researcher. In this type of work, the adult researcher can be seen as a figure of authority and control, rather than an equal (Mishna, Antle, & Regehr, 2004; Shaw, Brady & Davey, 2011). This can be problematic in terms of fostering trust and rapport with participants, and in facilitating personal disclosure. For sensitive topics such as continence, it is particularly important to think about how to approach this and redress the balance. Conducting face to face interviews can be highly intrusive as the researcher is coming into a participant's home environment; with Skype and telephone interviews, a sense of distance can be maintained. In this work, participants had more options regarding where the interview took place, e.g. if they were on a telephone or a laptop they could take this into their bedroom or another private space. I also made it clear to participants that they were in control of the interview and that they could end it at any time. Rather than terminating the interview and still having me in the house, putting down the phone or ending a video chat meant that they were immediately removed from the interaction. Participants responded positively to this, and very much liked being able to talk about their problems in their own personal space. During video chats, this also served as an icebreaker as I could ask about their posters and pictures, or they could show me different things in their room.

Familiarity with the communication method

Communicating by mobile phone or Skype is increasingly common, particularly for young people. Whilst the formal face to face research interview is an unfamiliar interaction for most children and young people, chatting remotely to friends or family using facetime or other similar applications is fairly common. By using the same communication method to conduct interviews, it removed much of the uncertainty about what to expect and how the interview would work. In other populations, such as older people or developing countries, the same familiarity may not be present; however for these young people, this type of communication was very much in keeping with their day to day life.

Researcher burden

A lot of methodological work, including this commentary, focuses on the participants. From a researcher perspective however, it is also important to consider the impact on us, the people carrying out the work itself. Conducting qualitative work on personal and sensitive topics can have a considerable impact on researchers at an emotional and individual level. Quite often we are told distressing information about a participant's experiences or life, and need to be proficient at knowing what to do when a participant becomes upset during an interview. Whilst we recognise this as part of the work, and indeed often seek to better understand these personal stories and experiences, it is important not to underestimate the emotional burden it places on us. During this work, I was told several stories which stayed with me long after the interview was over, and took time to digest and process. In previous work where I have conducted this type of interview in someone's home, this impact has been even greater. Even when the interview was over, I was still in their house continuing my interaction with them, on unfamiliar ground. Once I had left, I then often had a long journey back to the office by myself with no one to discuss my experiences or talk through any distressing events. In conducting the interviews in this study remotely, as soon as the interview was over I was back in the office with colleagues immediately available for support and advice. Being able to share my feelings or experiences within my team and gain support was hugely valuable. Rather than sitting with uncomfortable emotions or turning over events in my head for hours before I was able to talk about them, this remote method of working offered immediate contact and access to support.

Remote data collection also removes any issues around lone worker safety and concerns about putting researchers in dangerous situations. Although with this participant group it is highly unlikely that anything dangerous would happen during a face to face interview, it must always be considered, and procedures put into place. For Skype and telephone interviews, the researcher is not placed in any danger by attending individual homes or remote locations, but can conduct their work from their own office.

Conclusion

This study exploring the impact of continence problems on young people offered the opportunity to conduct remote data collection by Skype and telephone. Whilst I did experience technical problems, and challenges around building rapport, my overall experience with this method has been highly positive. Skype video interviews in particular have a lot to offer as a data collection method, in terms of access to diverse geographical locations and populations. Digital communication is becoming increasingly common and it is vital we share our experiences of research with this medium.

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